

The Importance of Palliative Care for Dementia. Commentary on Lee et al., A
Complex Clinical Intersection: Palliative Care in patients with Dementia

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Palliative care is broadly recognized as an essential treatment model for providing effective, comprehensive, and transdisciplinary care for those with progressive, life-limiting illnesses (1). Dementia has been increasingly recognized as one of these illnesses, and indeed a life-altering illness for families and a life-limiting illness for patients (2). The interface of psychiatry and palliative care also has been increasingly recognized as important for providing the best whole-person, patient/family centered care (3, 4). The article by Lee et al. in this issue touches briefly on a few of the important topics to consider when taking a palliative care approach to dementia care. We hope to expand upon some of what was covered by Lee et al and point readers to resources for further improving their approach to patients with dementia.

To begin, the management of neuropsychiatric symptoms is a challenging, very briefly touched on in this review, with the literature plagued by 1) heterogeneity in terminology and focus (neuropsychiatric symptoms, behavioral and psychological symptoms of dementia (BPSD), and symptoms of agitation, aggression, apathy, anxiety, etc.); 2) heterogeneity in measures; 3) studies of limited size or quality; and 4) a conflicting or weak evidence base (5). Yet, there are guiding principles, based on existing evidence, guidelines, and expert opinion, that may help in managing neuropsychiatric symptoms, which would be helpful to add. Many approaches and algorithms exist, DICE (Describe, Investigate, Create, Evaluate) (5) is one, but having and using a standardized approach may be more important than debating the merits of any one of these. Most importantly:

- Ensuring an accurate diagnosis of dementia, including the specific etiology.
Patients with frontotemporal dementias may present with depression, apathy or behavioral symptoms predominating over cognitive issues. Patients with dementia from Parkinson's disease or Dementia with Lewy Bodies are both at increased risk of hallucinations and are more susceptible to adverse effects of anti-psychotic medications.
- Considering delirium if symptoms are new, and if there is an acute change, where the provider should investigate for underlying, reversible, medical conditions.
- Categorizing behavior and symptoms, searching for precipitants, and attempting to manage non-pharmacologically when not severe or risking the safety of patients or others.
- Becoming familiar with programs that may reduce the occurrence or severity of neuropsychiatric symptoms, such as PREVENT (6) or communication/interaction training programs for caregivers and staff through many organizations including local chapters of the Alzheimer's Association.
- Considering other non-pharmacological interventions; while less proven in trials, individual patients may respond to music therapy, aromatherapy, and other integrative medicine approaches.
- When psychoactive medications are needed because of persistent or severe symptoms, be clear with the patient and family about the symptom being targeted (e.g., delusions, hallucinations, anxiety, etc.) and how they and you will judge if the medication is working. Set realistic goals, educate about potential side effects to watch for and their absolute (as opposed to relative risk), and have a plan for

frequent communication – by phone in between office visits may work well in some cases – to judge response to medication and titrate or change treatments (7).

- Understanding how different care settings, such as nursing homes, bring their own opportunities and challenges, including staff issues, work flow, and anti-psychotic use policies, with dementia being a target of a nation-wide program to reduce usage.
- Providing assistance to family and caregivers who often are severely stressed and in need of support and services. Practices need to be able to refer caregivers to helpful resources like the local chapter of the Alzheimer's Association, local Area Agency on Aging, and other community organizations. There is also the potential to facilitate mental health services for caregivers given the prevalence of stress/burnout, depression, and sleep disturbances in these individuals.

The assessment of pain deserves further comment as well, with its close relationship to quality of life and being a foundational element of palliative care. Appropriate pain assessment and intervention should be the responsibility of every clinician caring for persons with dementia (8, 9). The importance of pain as highlighted in the article is corroborated by the recently updated 2015 Dementia management measurement set from the American Academy of Neurology which now includes the measure, "Pain assessment and follow-up for patients with dementia". As the literature continues to document the association between pain and agitation and aggression, improvements in pain assessment and management remain paramount. Given the communication and memory changes with dementia, clinicians should integrate a multifaceted pain

assessment that incorporates patient self-report, evaluation for painful conditions, caregiver report, and a real-time assessment of pain behaviors. If pain or discomfort are apparent or a possibility based upon the evaluation, an analgesic trial should be initiated and evaluated to determine if the targeted behavior improves with pain treatment. Providers should integrate a multi-modal pain management strategy that incorporates non-pharmacologic and pharmacologic approaches, as well as an interdisciplinary approach.

Another key component of palliative care that deserves further comment is the principle that the care one receives is consistent with one's care preferences. For example, the overwhelming majority of people want to be home at the end of life, but this only occurs for a minority of patients. Ongoing advance care planning serves a critical tool to increase the likelihood that care is consistent with wishes (9, 10). Persons with dementia represent a particularly important population to engage in advance care planning, since decision-making capacity is lost with disease progression, and the most complex decisions such as artificial nutrition and hydration, antibiotics, and the role of hospice often occur in advance stages of dementia. The significance of advance care planning is again supported by the 2015 Dementia management measurement set, which advocates for an advance care plan as well as the appointment of a surrogate decision-maker (9). Moreover, CMS now supports advance care planning through reimbursement of the conversation by a physician, nurse practitioner, or physician assistant through time-based CPT codes that can be used on the same day as encounters if the time elements for each are distinct. As the authors indicate, many evidence-based tools exist to complete an advance care plan including a more general

strategy through “Five Wishes” to a much more specific care plan as dementia progresses through POLST (The Physicians Orders for Life Sustaining Treatment (POLST)). Taken together, all clinicians have a role to ensure care is consistent with wishes and that the resources and tools exist to further integrate palliative care into dementia care through improvements in advance care planning.

This commentary, in addition to the article by Lee et al., will hopefully point the reader in the direction of applying palliative care principles of preventing and relieving suffering through whole-person care, including exquisite diagnosis, symptom prevention and management (pharmacological and non-pharmacological approaches), prognostication, evolving advance care planning, care for the patient and family across all domains of potential suffering, and use of both palliative care and hospice services as an extra layer of support for the providers, patient, and family, preferably sooner rather than later (11).

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